ORIGINAL ARTICLE

Family resources and promotion of development of children with cerebral palsy

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Abstract

Introduction: Cerebral palsy (CP) describes a group of permanent disorders of movement and posture, causing activity limitation, attributed to a non-progressive disorder that occurs in the developing brain. The family of a child with CP becomes essential and will be much in demand, both to drive the child's development in a favourable environment and to maintain his health. A well-functioning family and a variety of environmental stimuli can be decisive in supporting children with CP.

Objective: To analyse family dynamics and the availability of child development-promoting resources in the family environment of children with CP.

Methods: We recruited a sample of 25 mothers of children with CP in the Hospital das Clínicas of Ribeirão Preto. Mothers completed the Family Adaptability and Cohesion Evaluation Scale (FACES IV), the Inventory of the Family Environment Resources (FER) and a sociodemographic questionnaire.

Results: The average age of mothers was 32.3 (±7.6) years; 68 per cent had completed at least primary education and 80 per cent were living with a partner. The average age of the children was 48.0 (±15.5) months; 56 per cent were girls and 68 per cent attended day care or preschool. Moderate correlations were observed between environmental resources and family functioning ($0.39<r<0.70$), and the FACES IV indicative scales of good family functioning showed positive correlations with the overall score of FER.

Conclusion: Children with CP have few opportunities to participate in activities outside the home, but have received a good supply of resources in their homes. Well-functioning family dynamics showed an association with a greater supply of resources in the domestic environment.

Keywords: cerebral palsy, family, child development, protective factors, family relations

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INTRODUCTION

Cerebral palsy (CP) is a risk condition for child development and triggers a number of situations that may aggravate or protect children and their development. CP, or non-progressive chronic childhood encephalopathy, describes a group of permanent disorders of development, movement and posture, causing activity limitation and is attributed to a non-progressive disorder that occurs in the brain during foetal development or during childhood. Motor disorders are often accompanied by sensory, cognitive, behavioural, epileptic and musculoskeletal secondary alterations[1,2].

CP may be a consequence of pre-, peri- or postnatal events such as intraventricular haemorrhage in preterm infants, consumption of alcohol and cocaine during pregnancy, infections in the mother or in the child himself (rubella, toxoplasmosis, cytomegalovirus, meningitis), placenta displacement, asphyxia, birth accident, cranioencephalic trauma, prematurity, low birth weight and meningoencephalitis in the newborn[1,3].

Classification of CP can be made by the dominant clinical characteristics: spastic, dyskinetic and ataxic; by the affected limbs (hemiparesis, diplegia and quadriplegia); according to the motor impairment of the global motor functions (GMFCS I to V); and according to anatomical distribution, unilateral (monoparetic, hemiparetic) and bilateral (diparetic, triparetic, quadriparetic)[1,4].

With the advancement of health resources, the survival of children at risk or with any complication has been favoured, with a tendency to increase these rates. In the last five decades, there has been an improvement in neonatal and obstetric care, resulting in a significant decline in infant mortality. Due to this, there is great clinical and scientific concern about the increase of children born with neurological sequelae[2].

There are no prevalence data about CP in Brazil. Some authors[1,5,6] comment that in developing countries the incidence of this disorder is seven per 1000, and Brazil sees about 30,000 to 40,000 new cases per year. However, such data are from the beginning of the 2000s, lacking up-to-date studies.

The damage resulting from CP can be varied and may include cognitive, visual and auditory problems, as well as motor and sensory dysfunctions, interfering in all infant development and imposing functional limitations and dependence on other people[6].

Thus, the family of the child with CP, considering all the characteristics of the disorder, becomes essential and will be very much required both to lead the child's development in a favourable environment and in the care and maintenance of their health condition. The child with CP will require from the mother and the family greater patience and sensitivity in order to gain security about his surrounding world, to develop at his own pace and to establish a positive bond with the environment, starting from his potentialities[3].

Some authors[7,8] point to a series of factors present in the family environment that can negatively affect child development: parental unemployment and financial problems; low maternal schooling; conjugal fights; limited expectations of parents regarding child development; physical and emotional abuse of children; negligence or limited mother/baby interaction; the presence of four or more children; poor performance of family roles; and values, rules and communication.

Other factors may favour development. Autonomy, a positive social condition, union and family support, the adoption of a daily routine, communication strategies that facilitates the understanding of needs, and the help of relatives and social protections contribute to attenuate or neutralize the effect of adverse conditions on development. Good family functioning and a wide range of environmental stimuli can be essential in supporting CP children[7].

It is important to consider that, during childhood, children are exposed to various stimuli and develop skills that help to boost their development, establishing an interaction with the environment in which they live. This influences and is influenced by the child, contributing to the development process[9]. However, childhood diseases are a point of negative interference in the development of the child, unbalancing his organism and, consequently, the environment around him.

Considering that there is an interaction between the cognitive, social, affective and physical aspects, one must look at all of them in studying child development, how they integrate and how changes in these different dimensions of development can impact on the child, the family and his environment.

Changes have been occurring in families due to the intense participation of women (mothers) in the labour market, increasing family diversity and new ways of looking at the family system, but the family continues to be the main context of children's socialization, becoming the great caregiver, transmitting values and organizing the life and routine of younger members[10].

Most of the studies on CP have focused on the clinical aspects. However, considering the importance of the role of the family in this context and the limited number of studies regarding the psychosocial aspects involved in the condition of CP in childhood, the objective of this study was to analyse the family dynamics and the availability of development-promoting resources in the family environment of children with cerebral palsy.

METHODS

This is a cross-sectional, descriptive and correlational study with quantitative data analysis and inclusion criteria previously determined. The research project was approved by the Research Ethics Committee of the Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto da Universidade de São Paulo (CAAE n. 27390114.1.0000.5440) and is in accordance with Resolution no. 466/12 of the National Health Council and the international norms of research with human beings, having adopted all the recommended ethical procedures. All participants signed the informed consent form.

Participants

A non-probabilistic sample of 25 mothers of children with CP diagnosis was recruited. All children were followed up at the Rehabilitation Centre (RC) or in the Childhood Spasticity and Dystonia (ESDI) and Child Neurorehabilitation (NRI) outpatient clinics, all in the Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto, Universidade de São Paulo.

The inclusion criteria for the study were to have a child with CP aged between two and seven years and to be older than 18 years old. The exclusion criteria were that the child had some psychiatric comorbidity or the mother had difficulty responding to the interview (informed by the service staff).

Instruments

The mothers of the patients were invited to fill out a questionnaire for the sociodemographic information of the participants (age, sex, education, marital and occupational status, economic class) and their children (gender, age, schooling, sibling presence).

The degree of impairment of motor function was measured by the Gross Motor Function Classification System[11] (GMFCS), based on observation of movement initiated voluntarily with an emphasis on sitting, transfer and mobility. Classification ranges from I (less impairment) to V (greater impairment), considering functional limitations, the need for manual mobility devices (such as walkers or crutches) or mobility on wheels, and the quality of movement. Descriptions of the function are given for each level, separated by age group. The focus of GMFCS is on determining which level best represents the abilities and limitations of gross motor function that the child or young person has.

The Family Cohesion and Adaptability Assessment Scale IV (FACES IV) was used to evaluate family functioning. The instrument consists of 62 items which are distributed in two balanced subscales (cohesion and flexibility), four unbalanced subscales (disengaged, enmeshed, chaotic and rigid) and two subscales that assess dimensions that facilitate family functioning (communication and satisfaction). Items are answered on a five-point Likert scale. The result is calculated from the combination of the scores of the balanced and unbalanced scales and allows differentiating between healthy and unhealthy families[12]. The Brazilian version was used, provided by the authors of the scale[13].

To evaluate the availability of resources in the environment, the Family Environment Resource[14] (FER) inventory was used, which addresses three domains: resources that promote family approximation; activities that show stability in family life; and practices that promote family-school linkage. The inventory is applied in interview format, filling the same from the mother's response. It consists of 101 items distributed in ten topics: recreational activities at home or in the neighbourhood; family outings; scheduled and regular activities; joint activities with parents at home; toys; newspapers and magazines; books; school support and supervision; organization of schedules; and family reunited for routine activities. The score is calculated by the total sum of items marked on each topic and the relative scores for each are calculated.

Procedure

Initial contact with the mothers was made at the outpatient clinic on the day of the child's appointment. All participants signed the informed consent form and the researcher, based on the information provided by the family member, filled out the instruments.

Data analysis

The data were stored in spreadsheets in SPSS 17.0 and descriptive analysis was performed. The Spearman's correlation test was applied to verify the associations between the resource variables and family functioning.

RESULTS

In this study, variables collected from 2,694 high schooThe mothers' ages ranged from 19 to 50 years (mean = 32.3±7.6 years); 68 per cent had completed at least primary education and 80 per cent lived with their partners. Only one participant resided alone with the child. Table 1 presents information about the mothers.

Table 1: Sociodemographic characteristics of mothers. Ribeirão Preto, São Paulo, Brazil, 2016.

Variable	Frequency	Percentage (%)
Schooling		
Illiterate/up to 3rd grade of elementary school	1	4,0
U to 4th grade	7	28,0
Completed elementary school	5	20,0
Completed high school	8	32,0
Completed higher school	4	16,0
Marital status		
No partner	5	20,0
With partner	20	80,0
Occupational status		
Works/ performs occupational activity	13	52,0
Does not work	12	48,0
Economic classification		
A	1	4,0

B	12	48,0
C	11	44,0
D	1	4,0

As for the children, the ages ranged from 24 to 77 months (mean = 48.0±15.5 months); 56 per cent were girls and 68 per cent attended day care or preschool, show in table 2.

Table 2: Sociodemographic characteristics and functional classification (GMFCS) of children. Ribeirão Preto, São Paulo, Brazil 2016.

Variable	Frequency	Percentage (%)
Sex		
Female	14	56,0
Male	11	44,0
Presence of siblings	15	60,0
Schooling		
Day care centre attendance	10	40,0
Preschool attendance	7	28,0
Does not attend	8	32,0
GMFCS		
I	3	12,0
II	8	32,0
III	4	16,0
IV	7	28,0
V	3	12,0
Child can walk		
Yes	16	64,0
No	9	36,0

Table 3 shows the results regarding the resources available in the family environment. It is observed that the topics with the highest indexes were: performing joint activities with parents at home; Presence of toys in the home and recreational activities in the home or neighborhood. The least available resource refers to scheduled or scheduled activities.

Regarding family functioning, three families (12 per cent) were considered dysfunctional. Table 4 shows the average results of the participants for each subscale of the FACES IV scale.

Table 3: Family environment resources. Ribeirão Preto, São Paulo, Brazil, 2016.

Topics	Minimum	Maximum	Media (±SD)
Recreational activities at home or in the neighbourhood	3,3	10,0	7,3 (±1,8)
Family outings	0,6	7,9	5,0(±1,9)
Scheduled and regular activities	0,0	6,2	1,9(±2,0)
Joint activities with parents at home	4,5	10,0	7,7(±1,6)
Toys	2,8	10,0	7,7(±2,2)
Newspapers and magazines	0,0	10,0	4,7(±3,1)
Books	0,0	10,0	5,8(±2,8)
School support and supervision	0,0	10,0	4,5(±3,5)
Organization of schedules	1,2	10,0	5,9(±1,9)
Family reunited for routine activities	1,7	10,0	6,5(±2,3)
Total score	3,0	8,3	5,8(±1,6)

As to associations between environmental resources and family functioning, moderate correlations ($0.39<r<0.70$) were observed, and positive or indicative of good family functioning (cohesion, flexibility, communication and satisfaction) on FACES IV had positive correlations with the overall FER score. All the correlations shown as significant are presented in Table 5.

The enmeshed and rigid subscales of FACES IV did not correlate with any environmental resource investigated. Resources related to joint activities with parents at home, organization of schedules and family reunited for routine activities did not correlate with family functioning.

Table 4: Family functioning subscales. Ribeirão Preto, São Paulo, Brazil, 2016

Subscale (minimum–maximum score of the subscale)	Sample minimum	Sample maximum	Media (±SD)
Cohesion (7–35)	19	35	30,9 (±4,3)
Flexibility (7–35)	16	35	27,7 (±5,7)
Disengaged (7–35)	7	30	13,3 (±5,4)
Enmeshed (7–35)	12	29	19,8 (±3,4)
Rigid (7–35)	7	32	20,0 (±6,0)
Chaotic (7–35)	8	29	15,4 (±6,0)
Communication (10–50)	13	50	42,0 (±9,0)
Satisfaction (10–50)	22	48	36,5 (±7,6)
Organization of schedules	1,2	10,0	5,9(±1,9)
Family reunited for routine activities	1,7	10,0	6,5(±2,3)
Total score	3,0	8,3	5,8(±1,6)

Table 5: Significant correlations (p<0.05) between environment resources (FER) and family functioning (FACES IV) (Spearman's correlation). Ribeirão Preto, São Paulo, Brazil, 2016.

Resources	Subscales for family functioning					
	Correlation coefficients (*r*)					
	Cohesion	Flexibility	Disengaged	Chaotic	Communication	Satisfaction
Recreational activities	0,409			-0,409		
Family outings	0,474		-0,408			
Scheduled activities	0,475					
Toys	0,444					
Newspapers and magazines	0,585	0,433			0,525	0,467
Books					0,401	
School Supervision			-0,405			
Total Score	0,580	0,442	-0,483		0,438	0,413

DISCUSSION

This study contributes to the expansion of knowledge about the influence of the family in the development of children with cerebral palsy and can contribute to the planning of actions that aim to promote the healthier development of these children.

The group of participating mothers is quite similar to that reported by other researchers, with young mothers who have good schooling and are professionally active[15].

It was observed that the majority of the families involved a couple (husband and wife), which constitutes a factor of protection in the child's development, since it allows the sharing of care and the offer of support to the main caretaker. Researchers[16,17] emphasize that the affective union of the parents, the close bonds of the children with the paternal image, and the support of the father in the routine of a family with CP tend to positively reinforce the psychomotor development of the child and to reduce the levels of familial stress. The presence of a paternal figure in the home can offer greater instrumental support with financial aid, transportation, drug costs and housing. The father/stepfather can also offer social support and emotional assistance with simple problem solving, attention, love, caring and understanding.

The predominant level of education in the sample (68 per cent of mothers with completed primary education or above) and the socioeconomic level of the families show that CP is a disorder that affects children regardless of cultural or financial conditions. In this sense, it is worth remembering that CP can be a consequence of different pre-, peri- or postnatal events that are not necessarily associated with precarious conditions of life[1,3].

Low parental education and belonging to the lower social class constitute risks to child development[7,8,17]. On the other hand, it is known that some conditions of the child, his/her family context and the wider context may improve the child's response to the risk of maladaptation[7]. Thus, considering that having CP is already a risk to the developmental process, the characteristics of the mothers and families found in this study can be established as conditions of protection for these children.

The diagnosis of CP significantly impacts families because they face frustration and psychological loss of the idealized child; they do not know the meaning of CP, the necessary care of the child and how he will develop. The demands of a child with CP alter the daily life of the family and provoke the reorganization of house routines, and family relationships, and changes in financial planning. Associated with this is the perception

of helplessness, insecurity and frustration in the face of the child's functional and developmental constraints and losses. Gradually, the family develops strategies to adapt to the context and the needs of the child to elaborate a new routine[18].

The care required by a child with CP can have a substantial impact on the family budget because it generates higher expenses than a child without CP, or because a family member needs to stop their activities outside the home (including work activities) to dedicate them to intensive care of the child[19]. It was observed that families seem to have developed strategies to cope with extra spending: mothers continued to work (many of them worked autonomously and turned their home into their working environment) and the couples remained united (mothers are supported by a spouse), minimizing the risks that could arise from the decrease in family income.

The good socioeconomic profile presented by the participants needs to be analysed with caution, since the research was carried out in a public tertiary care hospital which offers highly specialized care. One of the outpatient clinics where the participants were recruited performed a treatment with botulin toxin, which has a high cost and can be associated with physical therapy[20]. This treatment is not always available in the same service or through health plans due to the specificities of the procedure.

The fact that many children are not attending kindergarten or preschool draws attention because the school institution is a resource that can help and boost the comprehensive development of children. The law in Brazil provides for the inclusion of children with disabilities in regular schools or guarantees their education. There is a series of discussions on what is actually inclusion and about the rights of children with disabilities and their needs, which in general requires a number of adaptations of the school environment[21]. The difficulty in adaptation may be one of the barriers to childcare institutions and schools.

Attendance at kindergarten, pre-school and regular education is a protection factor for children's development[7]. In the case of children with CP, it is seen that many with higher motor impairment associated with other comorbidities, such as cognitive, social and language deficits, end up out of school and are not included in special education institutions[22]. This group of children, in particular, will depend exclusively on the resources available in the domestic environment to boost their development, and will depend much more on family interactions for their emotional and social development.

With regard to environmental resources, we can notice the predominance of activities carried out in the home or in the neighbourhood, mainly with the parents. Recreational activities involving the coordination and voluntary movement of the child are fundamental for the increase of psychomotor aspects, providing the maximum of development, self-confidence and leisure and minimizing the difficulties resulting from the CP[19].

As a result of the difficulties presented by children with CP, families are limited to the home environment, already adapted and more comfortable for them and the child. Without realizing it, they restrict the possibility of offering more resources and variety in social interactions.

It is in the social life that the child develops affective bonds, important for their behavioural development. However, the interpretation of how far the child is able to coexist harmoniously and how fragile he can be depends very much on the family's outlook, more specifically on the mother. When the interpretation of family members is greatly influenced by the child's pathology, this restricts his potential to explore the environment and his resources to do it[19].

The limitations resulting from CP also make it difficult to involve the child in other activities outside the home, as happens in school. Scheduled and regular activities outside the home environment (such as swimming, judo, ballet, music, among others), as well as tours, end up becoming restricted. The great majority of places for leisure and extracurricular activity, public or private, are not prepared to receive these children and their families.

Other authors[8,23,24] have already pointed out that families of children with chronic conditions spend more time involved in care activities than leisure. Healthcare comes first.

The restriction of leisure activities, the greater difficulty of access to extracurricular activities and to school itself, and the stigma faced by children and their families are reasons for the low incidence of out-of-home visits indicated by mothers, which are added to the financial difficulties stemming from increased costs of care and treatment.

It has also been shown that children with CP have more resources available in their family environment than other children but this is not true in terms of supervision of school activities by parents and organization of the daily routine[25,26].

On supervision of school activities by parents at home, a third of children with CP did not attend any kind of school or day care institution (kindergarten, pre-school or elementary school). As for those attending kindergarten and pre-school, the demand for homework was low or non-existent; hence there was no need for parental supervision.

The demand for healthcare (physiotherapy, occupational therapy, speech therapy, psych pedagogy, among others) and the need of assistance and support in daily activities on the part of the child makes it difficult to establish a routine, which justifies that among families of children with CP it is more difficult to organize well-defined schedules for the daily routine.

As for family dynamics, the families of children with CP are functional, with good relationships among the members. They show good cohesion (affective approach among family members) and good adaptability (flexibility, rules and roles defined and delimited), which is highlighted by better results in cohesion and flexibility (indicators of good family functioning).

Studies carried out in other cultures[27,28] in the context of health have revealed more difficulties related to family cohesion, flexibility and communication. This strengthens the idea that having a child with CP

alters family dynamics, and the family (group), as well as its individual members, develop psychological, interpersonal and care strategies to deal with the situation by adapting and moving on[18].

In front of a child with CP, especially when he is under seven years old, the family strives to remain cohesive as a strategy to support and cope with the situation. In this sense, the good communication skills present in the studied families are favourable to healthier family dynamics and can be decisive for good adaptation to the condition of the child.

Positive and healthy family functioning, predominant among the families studied, is a protective factor for the development of these children, strengthening the importance of family care in the treatment of children with CP.

Having the family as a partner in the treatment of the child with CP improves care of the child[18]. Family and child characteristics influence the type of treatment sought and offered to families[29].

Relationships between resources in the domestic environment and family functioning were observed. Cohesion among family members (defined as affective proximity among members) was largely associated with family resources. This aspect of family functioning rather than adaptive ability (flexibility) and communication skills seems to be decisive for good family dynamics in the context of CP. These families had already received the diagnosis and therefore had adjusted to it.

The limitations of the study are in terms of sample size and the use of a little known instrument, the Family Environment Resource inventory. As a strength, the research highlights the role of the family, especially the well-adapted one, in stimulating the development of children with CP. As previously pointed out, research on the psychosocial aspects of CP is still scarce compared to clinical studies and therapeutic advances aimed at improving motor functionality. It is suggested that special attention be given to the family in the context of CP treatment in order to promote and stimulate the development of children.

In conclusion, children with CP have few opportunities to participate in activities outside the home, but receive a good supply of resources in their homes. The good functioning of family dynamics shows an association with the greater supply of resources in the domestic environment.

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Resumo

Introdução: A Paralisia Cerebral (PC) descreve um grupo de desordens permanentes do movimento e da postura, causando limitação da atividade, atribuído a um distúrbio não progressivo que ocorre no cérebro em desenvolvimento. Assim, a família da criança com PC torna-se essencial e será muito exigida, tanto para conduzir o desenvolvimento da criança num ambiente favorável quanto para a manutenção de suas condições de saúde. Um bom funcionamento familiar e uma variedade de estímulos ambientais podem ser decisivos para apoiar a criança com PC.

Objetivo: Analisar a dinâmica familiar e a disponibilidade de recursos promotores de desenvolvimento infantil presentes no ambiente familiar de crianças com Paralisia Cerebral.

Método: Foi recrutada uma amostra de 25 mães de crianças com PC seguidas no Hospital das Clínicas de Ribeirão Preto. As mães preencheram a Escala de Avaliação da Coesão e Adaptabilidade Familiar (FACES IV), o Inventário de Recursos do Ambiente Familiar (RAF) e um questionário sociodemográfico.

Resultados: A idade média das mães foi de 32,3 (±7,6) anos, 68% com pelo menos o ensino fundamental completo e 80% viviam com companheiro. A idade média das crianças foi de 48,0 (±15,5) meses; 56% delas eram meninas e 68% das crianças da amostra frequentava creche ou pré-escola. Foram observadas correlações moderadas entre recursos ambientais e funcionamento familiar (0,39<r<0,70), sendo que as escalas indicativas de boa funcionalidade familiar do FACES IV apresentaram correlações positivas com o escore geral do RAF.

Conclusão: As crianças com PC têm poucas oportunidades de participação em atividades fora da casa, mas tem recebido uma boa oferta de recursos em seus lares. O bom funcionamento ou dinâmica familiar mostrou associação com a maior oferta de recursos no ambiente doméstico.

Palavras-chave: paralisia cerebral, familia, desenvolvimento infantil, fatores de proteção, relações familiares